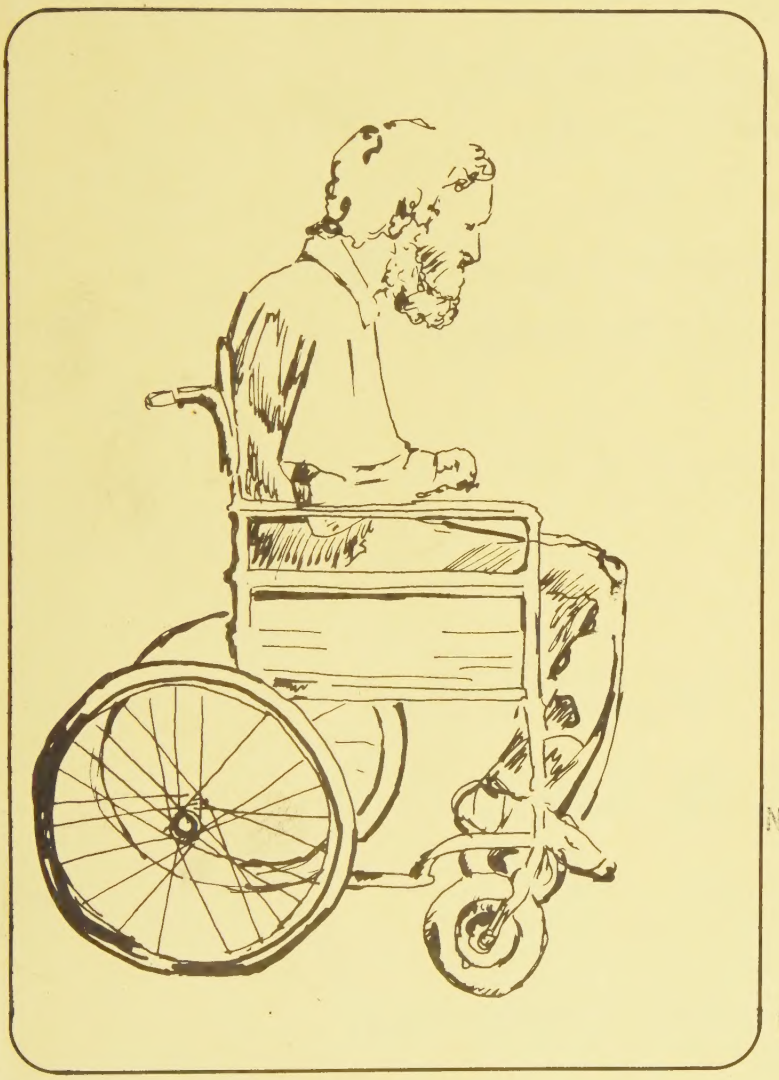
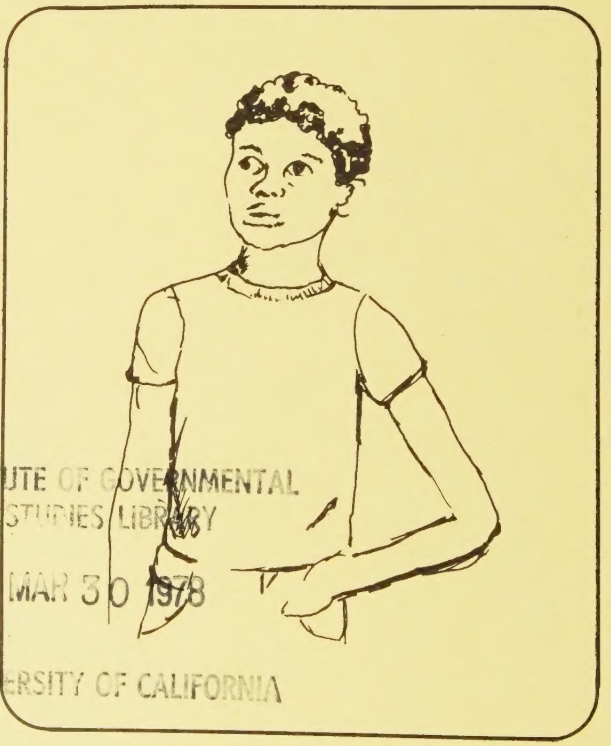
Alameda County Developmental Disabilities Planning And Advisory Council

Special Project

Fall 1977





SPECIAL PROJECT

FALL, 1977

Prepared and Submitted by:

PLANNING COMMITTEE and MEMBERS of the

BOARD OF DIRECTORS

of the

ALAMEDA COUNTY DEVELOPMENTAL DISABILITIES PLANNING AND ADVISORY COUNCIL

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ALAMEDA COUNTY HEALTH CARE SERVICES AGENCY

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Alameda County Developmental Disabilities Planning and Advisory Council works on behalf of people with developmental disabilities. Vignettes have been placed throughout the Project to emphasize the unique qualities of each person represented by the Council. They also demonstrate the value of a full spectrum of services for people with developmental disabilities.

SUMMARY OF SPECIAL PROJECT

Planning for people with developmental disabilities is one of the major responsibilities of the Board of Directors and general membership of the Alameda County Developmental Disabilities Planning and Advisory Council. As the result of a Funding Crisis experienced by the community serving the developmentally disabled in 1976, a Special Project was undertaken in lieu of an Annual Plan.

The goals of the Project are to more accurately document the number of Alameda County residents who are developmentally disabled, to assess their needs, to examine the funding systems which now make services available, and to make realistic recommendations for the implementation of needed services.

Of the 1,110,552 residents of Alameda County in 1976, there were an estimated 45,107 children and adults who were disabled by autism, cerebral palsy, epilepsy, mental retardation, and neurological handicaps. In an attempt to identify those developmentally disabled persons receiving services in 1976-77 a Survey was sent to Service Providers. Of the estimated 45,107 persons with developmental disabilities in Alameda County, the Survey revealed 13,958 County residents were receiving services for the developmentally disabled. Six hundred and eighty-six (686) of those receiving services were placed in State Hospital Programs. The remaining 13,272 persons were served in the community. There are projects underway by other programs to identify the unserved person with a developmental disability.

To identify needed services for developmental disabilities, a Continuum of Services was developed for both children and adults. A needs assessment, one part of the Survey, was used to document the gaps in the Continuum of Services. In addition to the Service Provider Survey, a Group Survey was used to assess the needs expressed by representatives of Parent Groups and Family Home Administrators. Interviews were conducted with developmentally disabled adults to determine the consumer needs. The identified needs are listed in the Project.

Information on funding sources for services provided to people with developmental disabilities was also collected from the Survey. Funding systems were identified by the respondents but many were unable to give figures. By going directly to the Funding Source, total amounts were given for expenditures for services in 1976-77. In some instances the specific amounts spent for services to the developmentally disabled were not delineated. Funding problems were shared by the respondents and have been included in the Project.

The members of the Board of Directors of the Alameda County Developmental Disabilities Planning and Advisory Council were asked to prioritize five of the identified needed services. The results are as follows:

1. RESPITE

   ISSUE: There are no Respite Facilities for children and adults with developmental disabilities in Alameda County.

2. COUNSELING

   ISSUE: There are inadequate counseling services in Alameda County for children and adults with developmental disabilities and their families.

3. TRANSPORTATION

   ISSUE: Present transportation services in Alameda County, public and private, are not adequate to serve the needs of the people with developmental disabilities and their families.

4. INDEPENDENT LIVING OPPORTUNITIES

   ISSUE: Adults with developmental disabilities need opportunities for independent living in appropriate units.

5. VOCATIONAL SERVICES

   ISSUE: Vocational Services for adults with developmental disabilities need to be expanded in Alameda County.

Elaboration on the issues and recommendations have been presented in the final chapter of the Project.

I. INTRODUCTION

The Lanterman Mental Retardation Services Act of 1969 established a statewide planning process for the orderly and economic development of services for the mentally retarded. Area Boards were created throughout California for the purpose of developing area wide plans. Alameda County was combined with four surrounding Counties--Contra Costa, San Francisco, San Mateo and Marin--to form Area Board V. In 1971, the Alameda County Board of Supervisors, by the passage of Resolution No. 136320, created the Mental Retardation Planning Committee for Alameda County. Subsequent legislation broadened the focus of the Lanterman Act to include developmental disabilities and, in Alameda County, resulted in changing the Mental Retardation Planning Committee to the Alameda County Developmental Disabilities Planning and Advisory Council.

The Council is now comprised of persons with developmental disabilities, their parents or relatives, professionals working in the field of developmental disabilities, and members of the public. Membership on the Council is open to all who are interested in working on behalf of the developmentally disabled. An elected Board of Directors, together with Staff, work across the broad spectrum of services--education, health, mental health, recreation, rehabilitation and social services--to provide coordination to the development and ministration of services.

The Council members accept their major responsibility as one of planning for the Alameda County residents, infants through aging adults, who are disabled by autism, cerebral palsy, epilepsy, mental retardation, and neurological handicaps. Since 1971 Plans have been presented to the Alameda County Board of Supervisors. During each planning phase the Council attempted to assess the needs of persons with developmental disabilities and have been faced with an underlying concern of working to develop a stable funding base for providing services.

The schedule for the planning cycle has been two years in advance. In the 1976-77 Plan, the Council addressed itself specifically to strengthening the funding sources to ensure continuity for the provision of services. During the planning process for 1977-78, the situation appeared ameliorated due to the introduction, passage, and implementation of the Lanterman Legislative Package (1976). This legislation is a series of ten bills which reviewed and amended previous legislation for developmentally disabled persons.

Following the presentation of the 1978-79 Plan to the Alameda County Board of Supervisors, the Council was confronted by a financial crisis which interrupted individual programs for many developmentally disabled children and adults. In turn the survival of community agencies was threatened. In November of 1976 the Council convened a Task Force on Funding Crises. Necessary steps to alleviate immediate problems were examined.

As a result of these efforts, the Task Force joined with the Developmental Disabilities Council's Planning Committee to undertake a Special Project. The goals of the Project are to more accurately document the number of Alameda County residents who are developmentally disabled, to assess their special needs, and to examine the funding systems which now make services available. From the recommendations presented in the Project, it is the hope of the Council that the Board of Supervisors together with other community bodies will assume leadership for ensuring a full spectrum of community based services for a special group of constituents in Alameda County, individuals with developmental disabilities.

"L" is a 7 month old boy, the first child of a couple who recently immigrated to the United States. His parents were looking forward to a baby. When "L" was born, his parents were making their home with aged paternal grandparents. The father had not yet found a job, but hope was still alive for these motivated people. It was known immediately that "L" was born with Down's Syndrome. A heart defect was discovered soon after. Medical treatment was begun immediately. Fortunately the medical staff recognized that this family was in need of other supportive services. The parents were referred to the Regional Center, where with the assistance of a bilingual interpreter, a progression of steps was initiated: assessment, diagnosis, and the development of a treatment plan.

A bilingual public health nurse began working with the child and his family. Understanding the cultural implications of producing a defective child, the nurse also undertook to help this family accept "L" and his special needs.

With medical care on-going and the family receiving support from both the Regional Center Counselor and the Public Health Nurse, it was time to introduce a new component in his developmental prescription, infant stimulation. This is a program designed to create an opportunity for developmentally delayed children to experience the normal steps in mastering their physical world. "L's" parents were taught at home to use special exercises for stimulating his physical growth and communication skills.

Today, "L" is the center of the family. His father has set up a small business for himself. Grandfather has accepted the responsibility of assisting mother with the stimulation exercises. The grandparents still do not know "L" has Down's Syndrome, but they do accept that he is a special child with very special needs.

II. DEMOGRAPHIC DATA

A. GENERAL POPULATION

Alameda County, covering a total area of 820 square miles of land and water, extends 35 miles from the San Francisco Bay through the hills to the San Joaquin Valley and reaches 50 miles from its southern most point to its northern boundaries. With an estimated population of 1,110,552, Alameda County is divided into two geographic regions referred to as North County and South County. The two regions are almost equal in population with South County gaining in population and North County remaining relatively stable.[1]

General population comparisons for the five Bay Area Counties are presented in TABLE 1.

TABLE 1

GENERAL POPULATION: AREA BOARD V [2]
1976 - 1978 - 1980

COUNTY	1976	1978	1980
ALAMEDA	1,110,552	1,126,496	1,143,829
CONTRA COSTA	611,691	631,686	652,798
MARIN	220,685	226,823	233,202
SAN FRANCISCO	669,536	665,204	661,118
SAN MATEO	576,005	584,373	593,119
TOTAL	3,188,469	3,234,582	3,284,066

[1] Chamber of Commerce, Research Department taken from an Official Statement, 2/8/77, made by the East Bay Municipal Utility District, Special District No. 1, page 19.

[2] Area Board V Developmental Disabilities Plan, January, 1977, page 9.

The following table and discussion was published by Area Board V, Developmental Disabilities Plan for 1977.

"Of great significance to relevant planning is a projection of population growth within each age group. As TABLE 2 shows, in the general population, the number of children aged 0-4 is expected to increase through 1980. The number of children aged 5-9, 10-14, and 15-19 is expected to decrease during this period. It is anticipated that the adult population, 20-64 and 65+, will rise in the next five years.

TABLE 2

GENERAL POPULATION BY AGE: AREA BOARD V
ALL COUNTIES

AGE	1976	1978	1980
0-4	213,830	227,330	241,750
5-9	224,420	218,440	213,820
10-14	256,840	236,660	225,210
15-19	267,680	267,330	259,200
20-64	1,898,399	1,944,772	1,990,886
65+	327,300	340,050	353,200
TOTAL	3,188,469	3,234,582	3,284,066

SOURCE: Department of Finance; Financial, Demographic and Economic Research

Although statistics for individual counties in Area V are not broken out in TABLE 2, there are several variations in county trends:

0-4 - an increase is projected for all counties in Area V.

5-9 - a decrease is projected for all counties in Area V.

10-14 - a decrease is projected for all counties in Area V.

15-19 - a steady decrease is projected for San Francisco and San Mateo Counties; however, an increase is projected for 1978 in Alameda, Contra Costa and Marin with a decline in these three Counties by 1980.

20-64 - an increase is projected for all counties in Area V except San Francisco, which will have a significant decrease.

65+ - an increase is projected for all five counties."

The ethnic and cultural distribution of the general population for Alameda County as determined by the 1970 Census is presented in TABLE 3.

TABLE 3

DISTRIBUTION OF THE POPULATION BY ETHNIC GROUP[1]

Alameda County

Ethnic Origin	Percent of Total Population
Caucasian	79.76
Black	15.03
Chinese	1.87
Filipino	.99
Japanese	.94
Indian	.53
All other	.88
Spanish Surname or Language	12.58

The primary survey conducted during the 1970 Census did not include a category for "Spanish Surname." Persons with a Spanish surname or who spoke Spanish as a primary language were included in the other categories. An estimate of 12.58 percent was determined for the Spanish Surname or Language based on a small sample taken from a secondary Census survey.

[1]Source: Bureau of the Census. U.S. Department of Commerce. Publications: 1970 Census of Population. General Population Characteristics for California, PC (1) - B6 and General Social and Economic Characteristics for California, PC (1) - C6.

B. POPULATION WITH DEVELOPMENTAL DISABILITIES

The definition of developmental disabilities used by the Alameda County Developmental Disabilities Planning and Advisory Council is as follows:

> " . . . a disability attributable to autism, cerebral palsy, epilepsy, mental retardation, or other neurologically handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals. Such disability originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial handicap for such individual."[1]

The definition found in the Lanterman Legislative Package (1976) no longer specifies a neurological handicap as a developmental disability.[2] The Federal definition of developmental disabilities in PL 94-103 includes one of the neurologically handicapping conditions, severe dyslexia.[3] Efforts are underway on both the Federal and State level to amend the definition of developmental disability.

For planning purposes it is necessary to have approximate numbers of the developmentally disabled people living in Alameda County. Prevalence rates are used for this purpose. They are determined by multiplying the general population figures by a specified percentage. A summary of epidemiological surveys conducted throughout the United States reveals that the rates vary depending on definition of the disabilities used and methodology of identification.[4] The California State Council on Developmental Disabilities Plan for 1978 records the range of prevalence rates to be:

Autism	0.005 percent to 0.01 percent
Cerebral Palsy	0.13 percent to 0.57 percent
Epilepsy	0.37 percent to 2.06 percent
Mental Retardation	1.8 percent to 3.5 percent[5]

For the purpose of this Project the Council has accepted prevalence rates used by Area Board V for planning purposes. They were established by the Department of Mental Hygiene several years ago and are still considered to be reasonable rates.

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[1] Alameda County Developmental Disabilities Planning and Advisory Council, Bylaws, Article II, Section A. February, 1977.

[2] Lanterman Legislative Package, 1976 (3800-3809).

[3] Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103).

[4] Mental Retardation: The Known and the Unknown, page 10. Century of Decision Series (President's Commission on Mental Retardation, 1976).

[5] California State Council on Developmental Disabilities State Plan, 1978-79, page 20.

Formulas derived are given below:

MENTAL RETARDATION

AGE	PREVALENCE RATES
0-4	.005 of general population
5-9	.022 of general population
10-14	.030 of general population
15-19	.025 of general population
20-64	.018 of general population
65+	.008 of general population
TOTAL	.018 of general population

The variance in percentages causes total figures to be different from sums of all of the age groups.

CEREBRAL PALSY

AGE	PREVALENCE RATES
0-20	2/1000 (.002) of general population
21+	1/1000 (.001) of general population

EPILEPSY

2% (.02) of general population; 20% (.20) of this number is considered to be substantially handicapped.[1]

AUTISM

Four per every 10,000 children are considered to be autistic. No prevalence figure is used for adults.

NEUROLOGICAL HANDICAPS

It is estimated that 5% of all children are neurologically handicapped. There is no formula for estimating the number of adults with neurological handicaps.

The prevalence of the five disability groups are found in TABLES 4 through 8. Figures appearing in these tables are derived from applying accepted prevalence rates to general population statistics. They are precise only to the degree that the prevalence rates are accurate.

[1]The Commission for Control of Epilepsy and Its Consequences in the Plan for Nationwide Action on Epilepsy, 1977, reveals new prevalence figures for epilepsy. One percent (.01) of the general population suffers from epilepsy. The new estimate is limited to those who presently have seizures or who are still taking medication to prevent them.

TABLE 4

PREVALENCE OF MENTALLY RETARDED BY AGE GROUP IN ALAMEDA COUNTY							
YEAR	0-4(1)	5-9(2)	10-14(3)	15-19(4)	20-64(5)	65+(6)	TOTAL OF POPULATION(7)
1976	403	1,832	2,787	2,485	11,650	857	19,990
1978	428	1,801	2,570	2,493	11,945	880	20,277
1980	454	1,773	2,460	2,426	12,242	906	20,589

(1) .005 of general population
(2) .022 of general population
(3) .030 of general population
(4) .025 of general population
(5) .018 of general population
(6) .008 of general population
(7) .018 of general population

The variance in percentages causes total figures to be different from the sums of all of the age groups.

TABLE 5

PREVALENCE OF CEREBRAL PALSY BY AGE GROUP IN ALAMEDA COUNTY			
YEAR	0-20(1)	21+(2)	TOTAL
1976	761	729	1490
1978	755	749	1504
1980	752	768	1520

(1) 2/1,000 (.002) of general population
(2) 1/1,000 (.001) of general population

TABLE 6

PREVALENCE OF EPILEPSY IN ALAMEDA COUNTY		
YEAR	Established Prevalence of Epilepsy in General Population (1)	Established Prevalence of Substantially Handicapping Epilepsy (2)
1976	22,211	4,442
1978	22,530	4,506
1980	22,877	4,575

(1) 2% (.02) of total population
(2) 20% (.20) of (1) figure

TABLE 7

PREVALENCE OF AUTISM IN IN CHILDREN IN ALAMEDA COUNTY	
YEAR	CHILDREN (1)
1976	152
1978	151
1980	150

(1) Four per 10,000 children. There is no prevalence figure used for adults.

TABLE 8

PREVALENCE OF NEUROLOGICALLY HANDICAPPING CONDITIONS IN CHILDREN IN ALAMEDA COUNTY	
YEAR	CHILDREN (1)
1976	19,033
1978	18,887
1980	18,805

(1) 5% (.05) of all children. No prevalence figures are used for adults.

Using current prevalence ratios for the five developmental disabilities, there were an estimated 45,107 people with developmental disabilities in Alameda County during the past year. See TABLE 9.

TABLE 9

ESTIMATED TOTAL PERSONS IN ALAMEDA COUNTY WITH DEVELOPMENTAL DISABILITIES BY DISABILITY

YEAR	MENTAL RETARDATION	CEREBRAL PALSY	EPILEPSY	AUTISM	NEUROLOGICAL HANDICAP	TOTAL
1976	19,990	1,490	4,442	152	19,033	45,107
1978	20,277	1,504	4,506	151	18,887	45,325
1980	20,589	1,520	4,575	150	18,805	45,639

To identify the exact number of people with developmental disabilities in Alameda County does not seem feasible. There are efforts underway to attempt to locate any person with a developmental disability who is in need of a service. Several case finding projects now in progress will be discussed later in the chapter.

The approach used for this Project is to document the number of developmentally disabled persons receiving services. Data was collected from a Survey mailed to 183 Service Providers.[1] Sixty percent (108) of the Surveys were returned. Thirty-three replied that the Agency could not provide the requested information, that they were no longer serving people with a developmental disability, or that they were no longer in business. From the remaining 75 respondents, a total of 13,958 people with developmental disabilities from Alameda County were identified as receiving services during 1976. See TABLE 10.

TABLE 10

NUMBER OF ALAMEDA COUNTY RESIDENTS WITH DEVELOPMENTAL DISABILITIES RECEIVING SERVICES IN 1976

LOCATION	NUMBER SERVED
Community Based Services	13,272
State Hospital Services (2)	686
TOTAL	13,958

[1]See copy of Survey in the Appendix.
[2]State of California Department of Health Biostatistics 1-21-77.

The developmentally disabled people receiving community-based services have been further described by the location of their residence, disability, age, and ethnic background. See TABLES 11 through 14.

TABLE 11

ALAMEDA COUNTY RESIDENTS WITH DEVELOPMENTAL DISABILITIES

NUMBER OF ALAMEDA COUNTY RESIDENTS
WITH DEVELOPMENTAL DISABILITIES
RECEIVING SERVICES IN ALAMEDA COUNTY IN 1976
BY GEOGRAPHIC LOCATION OF RESIDENCE

LOCATION	NUMBER SERVED	PRECENT OF TOTAL NUMBER SERVED
North County	6,001	45.2%
South County	3,319	25.0%
Out of County	676	5.1%
Not Stated *	3,276	24.7%
TOTAL	13,272	100.00%

*Fourteen respondents did not specify the geographic origin of their clients.

TABLE 12

NUMBER OF ALAMEDA COUNTY RESIDENTS
WITH DEVELOPMENTAL DISABILITIES
RECEIVING SERVICES IN ALAMEDA COUNTY IN 1976
BY TYPE OF DISABILITY

DISABILITY	NUMBER SERVED
Autism	131
Cerebral Palsy	794
Epilepsy	137
Mental Retardation	2,727
Neurological Handicap	2,430
Not Stated*	7,053
TOTAL	13,272

*Seventeen respondents did not specify disability.

TABLE 13

NUMBER OF ALAMEDA COUNTY RESIDENTS
WITH DEVELOPMENTAL DISABILITIES
RECEIVING SERVICES IN ALAMEDA COUNTY IN 1976
BY AGE BREAKDOWN

AGE	NUMBER SERVED	PERCENT OF TOTAL DEVELOPMENTALLY DISABLED PERSONS SERVED
0-5 years		
0-35 months 286		
3-5 years 322	608	4.6%
6-21 years	4,892	36.9%
22-54 years	641	4.8%
55+ years	78	.6%
Not Stated *	7,053	53.1%
TOTAL	13,272	100.0%

*Seventeen respondents did not specify the ages of their clients.

TABLE 14

NUMBER OF ALAMEDA COUNTY RESIDENTS
WITH DEVELOPMENTAL DISABILITIES
RECEIVING SERVICES IN ALAMEDA COUNTY IN 1976
BY ETHNIC BACKGROUND

ETHNIC GROUP	NUMBER SERVED	PERCENT OF TOTAL NUMBER SERVED
Black	1,620	12.20%
Caucasian	3,807	28.68%
Chinese	69	.52%
Filipino	12	.09%
Japanese	34	.26%
Other Asian (Korean, Vietnamese)	64	.48%
Native American	25	.19%
Spanish Surname/ Latin American	500	3.76%
Other	95	.72%
No Response *	7,046	53.09%
TOTAL	13,272	100.00%

*Twenty respondents did not specify ethnic distribution of their clients.

The preceding information holds value for the Council because it represents an initial attempt to focus on special characteristics of the population for which the Council is responsible. In some instances 25 to 50 percent of the respondents were unable to provide a descriptive breakdown as requested. Several factors appear to be responsible for this: (1) agencies and programs involved in the Survey are in the formative stages with financial stability, adequate staffing and the provision of effective service the primary concerns of the administrators. For these Programs statistical collection is a luxury they cannot afford. (2) Some agencies report that they offer assistance to all disabled people without keeping separate statistics for the developmentally disabled. (3) Others provide services to the general population and report that they do not segregate at any level. The information from the State Hospitals does not include descriptive information on the hospital residents other than by County location.

For a comparison of the placement of persons with developmental disabilities in the California State Hospital system see TABLE 15 below.

TABLE 15

AREA BOARD V STATE HOSPITAL POPULATION[1]
From July 1, 1976 through December 31, 1976

State Hospital	NUMBER BY COUNTY IN AREA BOARD V					
	Alameda	Contra Costa	Marin	San Francisco	San Mateo	TOTAL
Agnews	159	28	10	77	76	350
Camarillo	0	0	1	0	1	2
Fairview	3	0	1	2	3	9
Napa	71	30	16	59	26	202
Pacific	0	0	1	1	0	2
Porterville	18	9	3	16	13	59
Patton	1	0	0	0	0	1
Sonoma	407	210	77	333	171	1,198
Stockton	27	18	3	39	11	98
TOTAL	686	295	112	527	301	1,921

[1]State of California Department of Health Biostatistics, 1-21-77.

The outreach projects mentioned previously were designed to identify and assess the needs of the unserved population with developmental disabilities among others. At the completion of this Project, one of the outreach projects had published their results. It is important to list them so that the findings can be incorporated into future planning.

1. The Search and Serve Project, conducted by the California State Department of Education, is designed to identify all children with exceptional needs, assess their abilities and provide an Individualized Education Program (I.E.P.) for each identified person.

2. The State Department of Rehabilitation is conducting a statewide survey to accurately determine the size of California's adult disabled population and assess their needs.

3. The City of San Leandro, Human Resources' Department, has undertaken a needs assessment for handicapped people in San Leandro.

4. The National Significance Project was awarded to the United Cerebral Palsy Association of California, Inc., by the Developmental Disabilities Office, Office of Human Development, Health, Education and Welfare. The purpose of the project is to develop a model of services for those persons with developmental disabilities who are not mentally retarded.

5. A/C Transit has conducted a transportation needs assessment for all handicapped and aged persons in Alameda and Contra Costa Counties. The results will be discussed in the RECOMMENDATIONS.

The chasm found between the statistically predicted prevalence of persons with developmental disabilities and those actually identified will begin to close as the science of determining prevalence ratios is perfected and as projects are supported to seek out the unserved. It is the hope of the Council that a statistical figure will not be a deterrent to serving a developmentally disabled person in need.

"D" is a 10 year old boy who rides the bus to school everyday like his brother and sister. But his school is different. "D" is autistic. Until the age of 7, he could not feed himself, take care of his toileting, talk or respond to affection. His major past time was rocking back and forth on his bed. His father was serving in the military so that he was often absent from the family for long periods of time. "D's" mother had no one to care for him. He was consuming all of her attention which in turn alienated his brother and sister. There were times that "D" didn't sleep at night and his mother kept vigil in front of his door so that he could not leave during the night. His mother's inner strengths were her salvation. No community agency was helping her. She enrolled "D" in a special program for autistic children and fought for transportation costs from the public schools. But "D" suffered severe gastro-intestinal problems so much of the time that he was unable to benefit from the program. Drugs did not help him.

In desperation his mother talked with a physician who uses a dietary regime to bring the body into a healthy state so that the mind can begin to function at its own level. The diet worked for "D"; his physical probelms subsided. He had periods of quiet; words began to come; and he mastered his toileting. Mother hastens to explain that the diet does not work for all autistic children, but it does for "D".

His development has continued during the last 3 years. He was enrolled in the special class, attends a recreation program on Saturdays and Day Camp in the summer. One of his great achievements was winning a blue ribbon in the Special Olympics.

"D" is still a child. With the onset of adolescence and adulthood his needs will change and new problems will be encountered. Working with the autistic person is a new science. It is certain to develop as the community is asked to care for these unique people.

III. A MODEL CONTINUUM OF SERVICES FOR CHILDREN AND ADULTS WITH DEVELOPMENTAL DISABILITIES.

The State of California has officially recognized that developmentally disabled people are valued citizens of the State and their communities. As such, their rights to a full and protected life have been mandated by Federal and State law.[1]

The passage of the Lanterman Legislative Package of 1976 has further defined standards ensuring quality care for the person with a developmental disability. An important aspect of that assurance is effective planning. General Provisions of the Legislative Package (38001) state that:

> " . . . The complexities of providing services to developmentally disabled persons require the coordinated services of many state departments and community agencies to insure that no gaps occur in communication or provision of services.
>
> Services should be planned and provided as part of a continuum. A pattern of facilities and services should be established which is sufficiently complete to meet the needs of each person with developmental disabilities, regardless of age or degree of handicap, and at each state of life. To the maximum extent feasible, services should be available throughout the State to prevent the dislocation of persons with developmental disabilities from their home communities.
>
> Services should be available to enable persons with developmental disabilities to approximate the pattern of everyday living available to nondisabled people of the same age . . . "[2]

It, therefore, is appropriate for the Alameda County Developmental Disabilities Planning and Advisory Council to incorporate the concept of a *Continuum* into planning on the local level. The purpose of the *Continuum* is to assist in delineating needs of the developmentally disabled in Alameda County and in identifying gaps in the pattern of services. A Model

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[1] Developmentally Disabled Assistance and Bill of Rights Act, (PL 94-103) and the Lanterman Legislative Package (1976).

[2] Lanterman Legislative Package (1976), (38002).

for a Continuum of Services for Children and Adults with Developmental Disabilities is presented on the following pages. The evolution of the *Continuum* began with the presentation of the 1978-79 Plan and has been expanded to include components expressed in the Lanterman Law (1976).[1]

Developing a pattern of services presents a difficult task. Several important considerations are:

(1) The *Continuum* must incorporate five disability groups, each having its own unique needs.

(2) Within each of the five disability groups there exists a spectrum of functional abilities from profound to mild.

(3) The services must cover the life span of the individual from infancy through aging.

(4) The definition of terms used in programs and services often vary.

(5) What may appear to be special services for the developmentally disabled person are often services taken for granted and readily available to people generally.

(6) A vital force will be operating within the *Continuum* . . . that of personal choice.

Taking these factors into account, an attempt was made to present as complete and as objective a picture as possible. Interviews were conducted with the Executive Directors of the Alameda County Association for the Mentally Retarded (ACAMR), United Cerebral Palsy (UCP), the Epilepsy League; the Presidents of the California Association for Neurologically Handicapped Children (CANHC), and the Northern Alameda County Chapter of CANHC, and the Alameda County Chapter of the National Society of Autistic Children. Parents and their disabled children were included in several sessions. Another perspective came from group discussions with service providers held during meetings of the Alameda County Developmental Disabilities Case Committee, the Adult Continuum Task Force, the the Planning Committeee of the Developmental Disabilities Council.

The theme of common needs ran throughout the *Continuum*. It is important to point out again, however, that an often repeated concern was for each individual to be free to operate within the *Continuum* as an individual with his/her own unique needs. The vignettes found throughout the Project will help to reinforce this point.

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[1] Lanterman Legislative Package (1976), (38001).

A MODEL FOR A CONTINUUM OF SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN ALAMEDA COUNTY

(WITH EMPHASIS ON LEAST RESTRICTIVE LIVING EXPERIENCES)

STATEMENT OF FACT: *The continuum presents an accepted series of services to ensure a complete life for children with developmental disabilities. This flexible pattern can be used by each child according to his/her unique needs.*

PROGRAM COORDINATION FOR INFANTS, PRE-SCHOOL AGE, CHILDREN AND YOUTH THROUGH

DEVELOPMENTAL, SUPPORTIVE AND PROTECTIVE SERVICES

FUNCTIONAL EVALUATION

- Diagnosis
- Developmental Evaluation
- Medical Services
- Nutrition

- Infant Stimulation
- Pre-School Program

- Occupational Therapy
- Physical Therapy
- Communication Therapy
- Play Therapy

- Dental Services
- Psychiatric Treatment

- Special Education Services (Private and Public)
- Basic Social Skills
- Independent Living Skills
- Pre-Vocational Training
- Social Adjustment Counseling (Including Sexuality)
- Recreation and Leisure Activities
- Religious Nurture
- Travel and Mobility Training

- Information and Referral
- Parent Counseling
- Parent Education
- Parent to Parent Support

- Social Services
- Respite Care
- Homemaker Services
- Day Care

- Family Counseling
- Sibling Counseling

- Out of Home Living Options

  Skilled Nursing Facility
  Nursery
  Residential Care
  Small Home Care

- Case Finding

- Advocacy

- Financial Assistance

- Insurance Coverage

- Guardianship

- Education of Public

- Protection of Human Rights

Alameda County Developmental Disabilities Planning and Advisory Council, 1977.

A MODEL FOR A CONTINUUM OF SERVICES FOR ADULTS WITH DEVELOPMENTAL DISABILITIES IN ALAMEDA COUNTY

(WITH EMPHASIS ON LEAST RESTRICTIVE LIVING EXPERIENCES)

STATEMENT OF FACT: *The continuum presents an accepted series of services to ensure a complete life for adults with developmental disabilities. This flexible pattern can be used by each adult according to his/her unique needs.*

PROGRAM COORDINATION FOR YOUNG ADULTS, ADULTS, AND OLDER ADULTS THROUGH

DEVELOPMENTAL, SUPPORTIVE AND PROTECTIVE SERVICES

FUNCTIONAL EVALUATION

- Continuing Education Services
- Self-Help Skills Training
- Basic Social Skills Training
- Independent Living Skills Training
- Travel and Mobility Training

- Pre-Vocational/Vocational Training
- Sheltered Work Activity
- Vocational Counseling
- Employment

- Physical Fitness
- Recreation and Leisure Activities
- Cultural Enrichment
- Religious Nurture

- Physical Therapy
- Occupational Therapy
- Communication Therapy
- Nutrition Education

- Medical Services
- Dental Services
- Psychological Services
- Social Adjustment Counseling
- Psychiatric Services

- Social Services
- Family Counseling
- Homemaker/Chore Service
- Respite

- Out-of-Home Living Options
  - Skilled Nursing Care
  - Small Home Care
  - Residential Care
  - Independent Living

- Marriage Counseling
- Genetic Counseling
- Parenting Education

- Transportation
- Drivers' Education

- Consumer Education
- Legal Assistance

- Accessibility

- Financial Assistance

- Advocacy

- Insurance Coverage

- Guardianship of Person and Property

- Life Annuity or Trust

- Education of the Public

- Protection of Human Rights

Alameda County Developmental Disabilities Planning and Advisory Council, 1977.

"J," an exceptionally bright 5 year old girl, developed serious complications during a bout with the Asian flu in 1972. Two months of intensive care saved "J's" life, but the illness damaged her brain.

She could not sit, talk, walk, feed herself, care for her toilet needs or make eye contact. "J's" family of four brothers and sisters felt a profound loss.

With the assistance of a medical social worker, the family was offered emotional support and directed to Crippled Children's Service which offered some financial relief for the costly medical care. "J" then entered the Kaiser-Rehabilitation Center in Vallejo for intensive physical therapy. Within a month she made her first sound and within two months she could walk. "J" returned to her family and home approximately six months after the onset of her illness. But she was a different child. The family had to learn new techniques to communicate with her as well as care for her physical needs.

"J" participated in a communication class at San Francisco State University where she made some progress, yet she was still unable to talk or make eye contact. In the Fall of that year, she was enrolled in the Trainable Mentally Retarded Class for a trial period, but it was not appropriate. "J" needed more individual attention than was available. The family was beginning to feel the strain of "J's" demands and the constant screaming sounds she made during the day. "J's" mother learned about a Respite Facility in San Mateo County which is designed to provide temporary care for developmentally disabled children and adults. Using the family's resources, "J" began using the Respite services periodically. The time away for "J" afforded her rich new experiences and the family a much needed rest.

"J" was then enrolled in one of the Development Centers for the Handicapped. Her growth was noticeable especially in the area of her relationships with other people. When vacation time came, "J" enjoyed two weeks at the Respite Facility. At this time the Regional Center was able to assist the family with the cost of the Respite Service.

"J" continued attending the Development Center full time and the Respite Program periodically. The strain of total care for "J", however, was taking its toll on the family. The parents discussed residential placement. "J" began to have epileptic seizures. The family agreed that she needed special care. A visit to a Residential School in Marin County convinced the parents that "J" would benefit from this special 24-hour environment. With the support from the Regional Center "J" has been living out of her home almost a year. Her family is still very much involved in "J's" life.

IV. NEEDS

A Needs Assessment to document gaps in the Continuum of Services was part of the Survey conducted. In addition to the Survey used with the Service Providers, a Survey was prepared to gather information from representatives of Parent and Family Care Home Administrator organizations and from adults with developmental disabilities.[1]

Of the 75 responding Service Providers, 70 percent completed the Needs Assessment by checking the services as "Not Available," or "Available but Not Adequate to Serve" their clients rather than giving a priority. The following list represents the top 25 percent of the checked services. They are listed alphabetically, not in order of value.

Adult Education
Advocacy
Counseling (individual)
Cultural Enrichment
Day Care (including After-School Programs)
Dental Services
Diagnosis and Evaluation
Education of the Public
Family Counseling
High Risk Follow-Up
Independent Living Opportunities (with attendant care; with case management)
Infant Stimulation
Parent Education
Parent Groups
Psychiatric Services (including Therapy, Residential Treatment, and 24-Hour Crisis Care)
Respite (including In-Home and Out-of-Home)
Therapies (including Speech, Occupational and Physical)
Transportation
Vocational Services (including Pre-Vocational)
Weekend Recreation Programs

[1]See copy of Group Survey in Appendix.

Leaders from groups representing Parents and Family Care Home Administrators were asked to complete a Survey by indicating the needs of their developmentally disabled children and adults. Fifty-three percent of the representatives responded with the following needs:

TOP PRIORITY NEEDS

Therapy Programs
Respite
Transportation
Funding for Programs
Adult Day Programs
Early Intervention
Education of Public and Professionals
Independent Living
Residential Care
Vocational Services
Recreation/Leisure Activities
Counseling
Dental Care
Financial Assistance for Individuals
Infant Stimulation
Medical Services
24-Hour Crisis Care
Advocacy
Day Care
Special Education
Parent Education

It must be pointed out that in both Surveys, categories reflecting financial assistance and program funding were included. Respondents rated these categories as vital needs. Since funding is the basis of providing all services it has been recognized as a common need which deserves special consideration.

Interviews were conducted with 15 adults disabled by cerebral palsy, epilepsy, mental retardation, and neurological handicaps by staff from two settings, Catholic Charities Service to the Retarded and the Pacific Rehabilitation Center. To prioritize personal needs is impossible, therefore, each persons's concerns will be presented.

The group facilitator from the Counseling Service of Catholic Charities Services to the Retarded, has shared the needs in the statements below:

" . . . One opinion was unanimous. They feel like social outcasts. They would like to see more publicity given to Developmental Disabilities. More news stories about their population, more public recognition that they exist, more acceptance by the large community. With this goes their desire for normalization, the opportunity to participate in the same activities and have the same life experiences as other people. A common complaint is their lack of sufficient money to dress decently, live adequately and purchase entertainment.

R, who led the discussion, is 30 years old. She lives in a group home and is progressing toward independence. She has mild C.P., a controlled seizure disorder and visual problems. She is probably mildly retarded. However, her learning disabilities and other handicaps make it unclear how retarded she actually is. She feels there is not enough available for mildly retarded people. Jobs, training, social activities, chance to achieve independence. She also feels that at least the higher functioning people ought to have more say in the planning and decision making.

P, a young man of 20, mildly retarded with learning disabilities also felt the S.S.I. grant was not sufficient for him to become independent. He is very sports minded and wanted discount tickets or reserved seats or some means of facilitating his attendance at sporting events. He has had several incidents on the street while waiting for public transit and would like a self defense course for the handicapped.

J, a moderately retarded man of 25 who has partially controlled grand mal seizures feels very outcast. 'No one will sit by me in church since I had a seizure there.' He wanted people to know more about retardation and epilepsy so they wouldn't be afraid of him. He felt it would help if they (the D.D. population) had an organization of their own, like the self-help groups of the physically disabled.

K, a young woman of 27 who is borderline retarded with mild C.P. that effects her speech echoed this - With such an organization information such as people looking for roommates and needing to travel with someone or share transportation could be exchanged.

G, a moderately retarded woman of 29 agreed. She felt the need of advocacy (someone to talk to about your problems, who would be there just to help you, not to tell you what to do) and mourned the loss of our counseling group which she saw as operating in this fashion.

C, a 23 year old man of mild to moderate retardation worries about his dependence on public transportation to get to his job and feels some provision should be made when transit systems have labor trouble to alleviate this. He also feels social activities for the D.D. 'lump us all together.' He would like to have a place to meet people of his own age and ability.

S, a mildly retarded 23 year old girl with learning disabilities worries about those who are more disabled. She wanted seats on public transportation reserved for the handicapped and agreed with J's suggestion of an organization where they could help each other.

R, a moderately retarded 23 year old man looks normal. He is black and is frequently hassled on BART and by authorities who mistake his lack of understanding or compliance of the rules. He feels people in public jobs need to be educated about D.D.

Efforts to steer the discussion into mundane things like housing or programs were of little avail. This group wants acceptance, their rights and normalization; they want friends, social activities and some power over their own destiny. They are willing to work, but not at meaningless tasks. They've had training programs that lead nowhere, a lot of loneliness and disappointment. They recognize their need for support, but don't wish to be controlled. These people who are so near normal want 'in' to normal society . . ."

The participants residing at Pacific Rehabilitation Center shared with their group leader that community acceptance and accessibility are the keys needed to open doors to their independence. The following statements demonstrate the need of the residents:

L, in her late 30's, is disabled by cerebral palsy and must use a wheel chair for mobility. Once married and the mother of a small child, L has experienced independence. She looks toward the day she can again live in an independent environment. Transportation, privacy and a voice in handling her own affairs lead her list of needs.

S, a young woman in her 20's, confined to a prone position due to her limitations expresses the need to have transportation to get out among other people. She would like to take advantage of regular Adult Education courses.

P, in his 20's, is physically limited and in need of attendant care. Yet he believes he can live on his own with assistance. Transportation and accessibility are also major needs for this young man.

M, a vibrant young woman who must use a wheel chair, attends classes at a local community college. She too sees a need for living independently with supportive services.

J, a middle aged woman, whose disability affects her mobility as well as her ability to communicate, makes herself quite clear in wanting to be accepted when she goes into the community. She believes that the public needs more education about disabled people.

It is the common human needs that determine what services are needed by the children and adults who are developmentally disabled. When services are not available or available but inadequate to serve all who need them, it is people who suffer.

"F", an active adolescent, functioning with superior intelligence in some academic areas, reads at the first grade level. "F" is neurologically handicapped which causes him serious learning problems and considerable frustration. When he is in an educational setting with the instructor, his unique abilities come forth. But with additional students in the room, "F" becomes easily distracted.

His family consists of other members who have had learning problems. His mother has particular interest in working to see that "F" gets the help he needs, but the family income level is such that resources are limited. A social worker was able to make arrangements for "F" to see a psychiatrist to assist him in resolving some other emotional problems.

"F's" teachers can see potential for leadership and a contribution to his community for him with appropriate remedial help. A request was made for the school psychologist to complete a diagnostic evaluation of "F's" learning abilities. The schools have a mandated responsibility for remediation, but a budget cutback affected the availability of diagnostic services. "F" will continue through school with or without the diagnostic evaluation, but his success or failure in school depends on the availability of these special services.

V. THE FUNDING SYSTEM

A. HISTORICAL VIEW

Historically, the families of the developmentally disabled person were encouraged to place their children in an institution. The cost was borne by the family or by the State with some reimbursement from the families. If the family chose to keep the child within the home, there were, by and large, few supportive services available for the child with special needs. With the advent of the Parent Associations during the 1940's and 50's, the policy of institutionalization and quality of institutional care were challenged. Community services began to develop as the result of hard work on the part of the parents. Unity of purpose was achieved with the creation of the National Association for Retarded Children and United Cerebral Palsy, in the late 40's and early 50's.

From that point on, efforts were directed toward developing stable and effective programs for persons with mental retardation and cerebral palsy living within the community and toward upgrading the level of care for those people living within the state hospitals. Public and private agencies began to work together. Lobbying from parent organizations brought recognition of their special problems by the Legislators. In 1960 John F. Kenneday, then President, introduced the concept of Government support for community-based programs for the mentally retarded. At that time California had already begun efforts to return residents of the state hospitals to live as active members of the community.

Since that time, further legislation on the Federal and State level has attempted to create an atmosphere of awareness and acceptance by defining the human rights of the developmentally disabled. New parent organizations have come into existence as the special needs have been added of people disabled by epilepsy, autism and neurological handicaps.

B. CURRENT VIEW

Today the responsibility for the administrative and financial support of the developmentally disabled population is still divided between public and private agencies. Parent groups continue to be very much involved. Families of the developmentally disabled remain the most prominent contributors to the financial support of their children and adults. The eventual strain on families has prompted legislators to recognize the necessity of governmental assistance. The graph on the following page depicts the sources of funds expended for direct service programs for the mentally retarded in the United States during 1970.

SOURCES OF FUNDS FOR
DIRECT SERVICES PROGRAMS FOR MENTALLY RETARDED
IN THE UNITED STATES, 1970
(In Millions)

Insurance and Philanthropy	Client Fees	Federal	State and Local
$83	$187	$388	$2,517
2.6%	5.9%	12.2%	79.3%

On the Federal level, resources have been made available directly and through states to provide an incentive for developing programs and services. The states have undertaken planning and program development to meet the needs created by their policies of "de-institutionalization." They have assumed major financial responsibility for providing direct services to the developmentally disabled population. Still the money made available for placement in the state institutions has not followed the developmentally disabled person back in the community when transfer occurs.

On the local level, programs have developed to meet the need of the developmentally disabled in the communty. They have had to struggle for start-up funding and then search exhaustively for on-going sources of revenues. Among these are Revenue Sharing, Title XX, and Regional Centers.

In 1976, at the request of the Alameda County Human Services Council, the Bay Area Social Planning Council conducted a study and published a report entitled Expenditures for Human Services in Alameda County During Fiscal Year 1974-75. The study revealed that during 1974-75, of the $662,495,000 expended for Human Services in Alameda County, $3,431,000 was expended for services to the developmentally disabled.

For a current financial picture of funding sources for services to the developmentally disabled in Alameda County, the Council attempted to gather similar information from the Survey sent to the Service Providers. Of the 75 respondents, only 26 were able to complete the Financial Section. The remaining 49 respondents gave the following reasons for not providing this vital information:

1. Agencies did not know the original source of their funds.

[1]Mental Retardation: Century of Decision (President's Committee on Mental Retardation, 1976), page 29.

2. Agencies serve the general population, or people with mental and physical handicaps and they could not break out specific monies expended for the population with developmental disabilities.

3. Agencies indicated their financial status was confidential.

Therefore, a current view of funding sources and amounts could not adequately be documented by the results of the Survey.

Major funding sources identified by the results of the Survey were contacted directly to determine expenditures for services to the developmentally disabled in Alameda County during 1976-77. The figures for Education reflect their 1975-76 budget. The results follow:

1. Crippled Children's Service had a total budget for 1976-77 of $1,278,000. The administration was unable to provide the amount expended specifically for those disabled by a developmental disability.

2. The State Department of Rehabilitation reported their 1976-77 Budget to include $1,876,053 for General Case Funds. Of that amount, $377,481 was expended for services to the developmentally disabled.

3. For the years 1975-76, Alameda County School Programs expended $2,667,483 on all Special Education Classes. The specific amounts expended on students with developmental disabilities was not available.

4. There were no Developmental Disabilities Formula Grant Monies awarded to programs in Alameda County during 1976 through Area Board V.

5. Private Foundations awarded several grants to programs serving the developmentally disabled in 1976-77, but the total amount of money was not available.

6. Medi-Cal expended $106,000,000 in Alameda County during 1976-77. The amount expended for persons with developmental disabilities was not available.

7. The total budget for Alameda County Mental Health Services in 1976-77 was $12,093,946. The amount expended on services for the developmentally disabled was unknown.

8. Regional Center of the East Bay had a budget of $2,800,000 for the first 10 months of operation during the fiscal year 1976-77. This money was allocated for two Counties--Alameda and Contra Costa. About 65% of the developmentally disabled clients came from Alameda County, but the exact amount of money spent for Alameda County residents was not delineated.

9. Revenue Sharing monies expended in Alameda County totaled $10,683,030. Of that amount, the programs serving the developmentally disabled received $197,684.

10. The Social Security District Office was unable to provide the amount of money expended in Alameda County for SSI/SSA and SSP benefits during 1976-77. The proportion of developmentally disabled beneficiaries to the total group of aged, blind and disabled was unknown. Figures are not compiled on the local level.

11. Title XX funds allocated to Alameda County in 1976-77 totaled $7,113,293 with $471,179 directed to programs for the developmentally disabled.

12. United Way awarded $3,257,132 to programs in Alameda County in 1976-77. Of that amount, $114,000 went to programs for the developmentally disabled.

13. The amount of money paid in Private Fees was not given.

Other vital information gathered from the 26 Surveys revealed that 15 of 26 agencies had a projected deficit for the fiscal year 1977-78. The projected deficits ranged from $2,000 to $453,600 and together totaled $1,354,551. The reasons given for their funding problems include:

1. The level of funding allowed does not meet the costs.

2. Generic services have not accepted their responsibility to serve people with developmental disabilities.

3. Regional Center allocations are not based on need.

4. Funding is tied to the client not to program; therefore, the stability of program depends on client enrollment and attendance.

5. The State funding cycle historically has been sporadic and causes delays and interruptions in the provision of services thereby affecting other funding based on client population.

6. Program development monies are being allocated but agencies are unsuccessful in obtaining financial assistance from community resources.

7. The charitable dollar is drying up.

8. Inflation causes increase in costs.

One of the goals for this Project is to examine the funding system by identifying programs which provide services and sources who provide the funding for services to the developmentally disabled. It seems clear from the information presented in this chapter that there are many systems involved; not all assume their responsibility to the person with a developmental disability.

The frustrations experienced in attempting to collect financial information reflect the frustrations experienced by programs and services struggling to create a sound funding base from which they can operate effectively and efficiently. Continual funding problems, which force programs to discontinue or curtail services or to postpone plans for expanding or developing new services, render families and the community unable to care for the disabled.

"M" is a 25 year old young woman who was placed out of the home when she was 3 years of age because of an alcoholic mother. Subsequently, "M" was found to be mildly retarded with some emotional problems occasionally affecting her ability to relate to other people.

Her placement in a small family care home provided the stability she needed. Enrollment in special education classes provided training in self-care, personal management and the development of cognitive skills.

Upon completion of the special education program, she attended a Workshop where she learned work habits and special vocational skills. "M" had a special interest in working with disabled children. After four years at the Workshop, the staff referred her to the Department of Rehabilitation. The vocational counselor developed a plan for "M" to work part-time in a convalescent hospital caring for disabled children. She worked there learning valuable skills and earning wages that reflected her abilities. "M" was layed off because of staff cutbacks, but she immediately enrolled in an Adult Education Program designed to train housekeepers to work in medical settings. Through this adult growth period, "M" made use of her Medi-Cal benefits to see a therapist who helped "M" emotionally stabilize her life. Today, at 25 years of age, "M" is living independently while preparing for her vocation as a housekeeper.

VI. PRIORITIES

The services identified in the NEEDS as "Not Available" reflect needs of all ages and degrees of handicaps. In order for the Council to effectively support the development of new services or strengthen existing programs, the most pressing needs must be identified. The members of the Board of Directors of the Developmental Disabilities Council, made up of representatives of consumers, parents, professionals, and general public,were asked to prioritize the top 25 percent of the needs recorded in the Surveys.

The services listed below represent the five priorities which the Council addresses in this Project.

RESPITE

Respite is a period of relief for the family from caring for a dependent person. It is also an opportunity for the dependent person to gain new experiences. The physical and emotional demands of a developmentally disabled person upon a family can be stressful. Respite as a service is designed to strengthen the family, provide new experiences for the disabled person, prevent family disintegration, and reduce the incidence of institutionalization.

COUNSELING

Counseling for people with developmental disabilities and their families is a service which offers assistance in making decisions in the area of life adjustment. It includes all levels of human development with special focus on unique needs of the developmentally disabled. Counseling is a mental health service--primarily preventive in nature.

TRANSPORTATION

Transportation is a service as vital for the developmentally disabled person as it is for the general public. The ability to be mobile in the society is necessary in order that the developmentally disabled person is able to participate and contribute to the community. Some developmentally disabled people have special transportation needs. Many need accessible public transportation.

INDEPENDENT LIVING OPPORTUNITIES

The experience of living as an adult--making decisions, choices and defining one's own life goals is part of human development. Adults with developmental disabilities need the opportunity to

experience this level of growth with supportive services available to them according to their ability.

VOCATIONAL SERVICES

Productivity is one of our society's measures of value. For many persons with developmental disabilities, vocational pursuits provide this level of esteem. Vocational services for the developmentally disabled are specially designed to make use of the person's assets in the world of work--sheltered or competitive.

"R" writes poetry. He is a middle aged man, profoundly physically disabled by cerebral palsy. A person with determination, he functions with normal intelligence, has a special talent for writing and uses a mouth wand to move himself about in his electric wheel chair. When "R" reached adulthood, he moved into a convalescent hospital because his physical needs were more than his mother could care. While there, "R" met other young people with varying abilities and similar dreams.

He attended some college courses and participated in a recreation program at the Cerebral Palsy Center. However, there was not enough activity for him and he became bored. "R" used his creative energies to begin preparing to move from the convalescent hospital into an apartment of his own.

"R" used all of his energies to make his plan work--combating the red tape of S.S.I. and Medi-Cal regulations. It took a year to save enough money to rent an apartment and to hire an attendant. "R" now receives S.S.I., Medi-Cal and Homemaker/Chore Service. He also has the moral support from his family and members of a self-help group.

It hasn't been easy. "R" is in his third apartment. Roommate and attendant problems have been a concern. But, he is now at the point of applying for admission to college with the assistance of the Department of Rehabilitation. His poetry is still important to him and he has succeeded in having several poems published.

VII. RECOMMENDATIONS

RESPITE

ISSUE: There are no Respite Facilities for children and adults with developmental disabilities in Alameda County.

Families need relief from the care of their children and adults who are developmentally disabled. For all parents a period of rest from caring for a child is healthy. For parents of a disabled child or adult, it is essential. The 24-hour demands placed on the parents and siblings of a disabled person often cause stress which can only be remedied by a period of separation. Respite is a relatively new term which is now recognized as a service designed to offer time away for both family and child to prevent or to relieve a stressful family environment. Respite is seen as a necessary component in the spectrum of special services needed to help a disabled person remain in the community. Respite provides a potential for the disabled person to experience independence and self-reliance. Without relief, parents may be faced with institutionalizing their disabled child or adult.

Alameda County, a county which has the fifth largest population of developmentally disabled people in California, has no Respite Facility.[1] Families must now use respite services in San Mateo, Marin or Contra Costa Counties--forty-five minutes to an hour's drive away. Some of these facilities give preference to their County's residents. In the first half of 1977, the Regional Center of the East Bay purchased respite services out of Alameda County for approximately 27 families per month. There is an occasional bed in a convalescent hospital or Family Care Home in Alameda County used for respite, but these few spots are limited and not always available. In most cases a hospital setting is inappropriate.

In-Home Respite Services were developed in the Fall of 1976 with Developmental Disabilities Formula Grant monies. This service recruits and trains providers to go into the home to care for the disabled person. The Service has experienced relative success during its first year in operation, even though a new service such as this often takes time and successful experience to sell itself. The Grant Funds have been expended and community resources for continuing the service are being explored.

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[1] California Council on Developmental Disabilities State Plan, 1978, page 37.

Respite has been selected as the FIRST *priority for consideration in this Project.* The need for respite has always been evident to parents and professionals working with the developmentally disabled and their families. In 1975 documentation of the need was undertaken. The Ad Hoc Committee on Respite distributed a questionnaire to families with developmentally disabled children and adults. The results were overwhelmingly in favor of developing both In-Home and Out-of-Home respite services.[1] Area Board V and Alameda County Developmental Disabilities Council has recognized Respite as a priority since 1975.

RECOMMENDATIONS:

The Alameda County Planning and Advisory Council recommends:

1. *That the Health Care Services Agency of Alameda County enter into contract with Children's Home Society as soon as possible to provide respite for children with developmental disabilities in qualified foster homes, located in both North and South Regions of the County.*

2. *That the Ad Hoc Respite Committee of the Developmental Disabilities Council continue working with community agencies toward the development of a Respite Facility to serve all age groups as well as all levels of disability.*

3. *That County-wide support be given to the development of a coordinated Respite Service encompassing both In-Home and Out-of-Home Respite Services.*

[1]See copy of Respite Questionnaire conducted in 1975 in Alameda County in the Appendix.

COUNSELING

ISSUE: There are inadequate counseling services in Alameda County for children and adults with developmental disabilities and their families.

Counseling is a professional service which helps an individual or a family make decisions and adaptations related to effective functioning. It provides skills necessary to cope with excessive demands. Counseling is a service which can prevent severe adjustment problems and their costly remedies.

There are few counseling services available in Alameda County specifically designed for the person with a developmental disability. The major mental health agencies, public and private, often are unable to handle the unique needs of the disabled person. The Child and Family Mental Health Center, in North Region, has provided a consultant in the field of developmental disabilities.

Counseling has been selected as the SECOND *priority for consideration in this Project.* Nineteen of the respondents to the Service Provider Survey indicated that they include counseling as an ancillary service. Counseling Services, one counseling program for the adult disabled, funded by a one-year Grant, terminated operation in July of 1977 because of the cessation of funding. The success of this program and the expressed need for similar programs were discussed earlier.

The Commission for the Control of Epilepsy and its Consequences in their Plan for Nationwide Action on Epilepsy, 1977, called for counseling to be made widely available to persons with epilepsy and their families. The Plan indicated that "the least understood and most neglected aspects of epilepsy are its associated social, psychological, and behavioral problems."[1]

In addition to social adjustment counseling and family counseling, other situations of special concern include sibling counseling, peer counseling and counseling for parents handicapped by developmental disabilities.

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[1] Plan for Nationwide Action on Epilepsy, 1977, Vol. 1, (The Commission for the Control of Epilepsy and its Consequences).

RECOMMENDATIONS:

The Alameda County Developmental Disabilities Planning and Advisory Council recommends:

1. *That consideration be given by Mental Health Services of Alameda County Health Care Services Agency to funding the Counseling Service program recently terminated and to the development of other programs which meet the unique counseling needs of this population.*

2. *That emphasis be placed on in-service training in the field of developmental disabilities for public and private agencies who could provide needed counseling services.*

TRANSPORTATION

ISSUE: Present transportation services in Alameda County, public and private, are not adequate to serve the needs of people with developmental disabilities and their families.

Transportation is an essential service needed to utilize all community resources and to participate in the community with the least restrictions. Mobility for the disabled person must be provided at all levels. The major source of transportation for most people with developmental disabilities is family members. Public schools provide bus service for their students. Other programs are often unable to provide transportation for their participants. With proper training and orientation, some persons with developmental disabilities can use public transportation. With accessible buses more could make use of the mass transit system.

Transportation has been selected as the THIRD *priority for consideration for this Project.* In the Spring of 1977, A/C Transit District contracted with Crain and Associates to conduct a survey of the needs of "transit-handicapped" people. The Council has expressed its concern about the approach used to reach the disabled person most in need of transportation services. The Survey reports that 66,000 people in the A/C Transit District (covering Alameda and Contra Costa Counties) are "transit-handicapped." Thirty-seven thousand people expressed a need for the assurance of a seat; 16,600 indicated they needed special door-to-door service, and 660 indicated they needed a wheel chair lift.[1]

The Metropolitan Transportation Commission has adopted a policy that would preclude State and Federal funding going to any bus purchase except wheel chair accessible buses beginning October, 1978. The policy requires that by January, 1987, all transit district buses must be wheel chair accessible or that equivalent service to the handicapped be provided. Ten years is a long period of time to wait for adequate transportation for many disabled people who need it now.

RECOMMENDATIONS:

The Alameda County Developmental Disabilities Planning and Advisory Council recommends:

1. *That the Alameda County Board of Supervisors work on behalf of their constituents with developmental disabilities by urging A/C Transit to begin immediately to provide adequate and accessible services for the disabled.*

[1] A/C Transit Elderly and Handicapped Planning Study - Analysis of Needs and Alternatives, 1977 (Crain and Associates, Menlo Park).

2. *That the A/C Transit District provide intensified in-service training for their staff emphasizing the needs of a person with developmental disabilities.*

3. *That A/C Transit District join in providing public information regarding services for the disabled to begin to change public attitudes.*

4. *That Public Schools include travel training for all special education students according to the ability of the student.*

5. *That parents be encouraged to involve their children and adults who have developmental disabilities in mobility training.*

INDEPENDENT LIVING OPPORTUNITIES

ISSUE: Adults with developmental disabilities need opportunities for independent living in appropriate units.

Living plans for adults with developmental disabilities range from State Hospital care to living on one's own. As a disabled person develops independent living skills, the goal is life with the least restrictions. Practical experience has shown that some developmentally disabled persons can live alone. Others may live independently with assistance of supportive services such as attendant care and/or case management. In 1971 United Cerebral Palsy conducted a Housing Study among their disabled clients. The results showed that 19 adults were interested in an independent living situation. Since that time two programs in Alameda County have instituted independent living training and experience.[1] Neither, however, have included the non-ambulatory who responded to the Cerebral Palsy Survey.

Independent living opportunities has been selected as the FOURTH *priority for consideration in this Project.* For the past two years the Council's Ad Hoc Committee on Housing has been working closely with Housing and Urban Development (HUD) and the local Housing Authorities to develop housing opportunities for the adults with developmental disabilities. Federal and State funds have been made available through Section 8 to provide supplemental rent monies for the aged and handicapped, including the developmentally disabled persons living in independent units. A newly established After Care Program is providing additional units for disabled persons who receive continuing care. To implement these programs, a three way effort is being carried out by the developmentally disabled person and their case managers; by staff from the Housing Authorities; and by building owners and their managers. Housing Authority staff have assisted in renting several units to mentally retarded adults who have shown the ability to live on their own.

Congregate housing where a small number of units are designed to provide independent living with shared supportive services is also a need. United Cerebral Palsy has been successful on a national level in working with Federal funds to create functional congregate housing for non-ambulatory adults.[2]

In the Spring of 1977 the Office of Independent Living for the Disabled (OILD) was created by HUD to work for housing opportunities for all disabled people. The following statement taken from the 1976 Mental Retardation

---

[1]Marrakech West, Berkeley and Clausen House, Oakland.

[2]Annual Report, 1976 (United Cerebral Palsy Associations, Inc.).

Report to the President is meaningful for all developmentally disabled people and seems to reflect the goal of OILD on the State and local level:

> "State law and local ordinances should protect the right of handicapped persons to appropriate residential arrangements. . . "[1]

To experience success in developing independent living units for the developmentally disabled persons, public attitudes must be changed, discriminatory regulations, standards and codes must be challenged.

RECOMMENDATIONS:

The Alameda County Developmental Disabilities Planning and Advisory Council recommends:

1. *That the Alameda County Social Service Agency ensures that the Homemaker/Chore Service is available to adults with developmental disabilities.*

2. *That the Alameda County Health Care Service Agency makes available the services of their health educators, dental educators, and nutritionists to programs offering supportive services to those adults who choose to live independently.*

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[1] Mental Retardation: Century of Decision (President's Committee on Mental Retardation, 1976), page 60.

VOCATIONAL SERVICES

ISSUE: Vocational services for adults with developmental disabilities need to be expanded in Alameda County.

A comparison of epidemiological studies reveals that the greatest discrepancy between statistically predicted prevalence of mental retardation and the identifiable mental retardation group occurs in the adult population. This discrepancy is evident in Alameda County. Among all of the developmentally disabled only 700 adults are receiving services out of a prevalence figure of approximately 25,000. One possible explanation for the disappearing disabled adult may be that with special education and vocational preparation, the adults have been able to function in the mainstream of society thus losing their label. Other reasons for the limited number of adults being served is under study and must be considered in future plans.[1] Recognition of the value of special vocational services for the person with developmental disabilities and of the potential for contribution to society is encouraging. It must be noted that not all persons with developmental disabilities are capable of functioning independently in society. However, with a focus on using abilities and developing special adaptations in the area of work, valued productivity is possible. Vocational services include pre-vocational training, skills evaluation, job training, work experience and sheltered or competitive employment.

Vocational services have been selected as the FIFTH *priority for consideration in this Project.* Beyond the services offered in the public education system, there are few mandated vocational services for adults with developmental disabilities. The vocational programs now available in Alameda County are constantly struggling for funding, which has impeded plans for expansion.

The Department of Rehabilitation, Adult Education, and Community Colleges have begun to accept responsibility for providing services to adults. Their involvement has strengthened existing vocational programs, but has also reinforced the need for additional services.

---

[1] Mental Retardation . . . the Known and the Unknown, 1976, (Century of Decision Series).

RECOMMENDATIONS:

The Alameda County Developmental Disabilities Planning and Advisory Council recommends:

1. *That the Alameda County Board of Supervisors offer support to those working on behalf of the implementation of a "Habilitation Division" of the State Department of Rehabilitation and other long range funding proposals.*

2. *That the Adult Continuum of Services developed by the Adult Continuum Task Force of the Alameda County Developmental Disabilities Council be used as a tool to identify vocational service needs.*

3. *That education be offered to the public on the employability of the developmentally disabled and their unique abilities.*

A P P E N D I X

PLANNING COMMITTEE

The Planning Committee is composed of members of the Board of Directors and the general membership of the Alameda County Developmental Disabilities Planning and Advisory Council.

Ruth Moroney, *Chairperson*
Associate Executive Director, Alameda County Association for the Mentally Retarded

Barbara Reeder, *Ex Officio Member*
Parent
Chairperson, Alameda County Developmental Disabilities Council
and Board of Directors

Roswitha Beck
Parent

Allen Cherry
Director, Community Resources
Development
Regional Center of the East Bay

Tanya Goldsmith
Parent
President, California Association
for Neurologically Handicapped
Children, Northern Chapter

Bettie Hamilton
Public

Nona Kirk
Assistant Director of Special
Education, Alameda County
Schools

Frances Smith
Executive Director, Epilepsy League
League of Alameda and
Contra Costa Counties

Douglas Sweeney
Executive Director, United Cerebral
Palsy of Alameda/Contra Costa
Counties, Inc.

Vicki Vigil
Director, Marrakech West

Monique Weil
Chief Social Worker
Child Development Center
Children's Hospital

Ernest Wing
Director, Spectrum

Acton Barnes, *Consultant*
Deputy Agency Director, Administration
Alameda County Health Care Services Agency

STAFF

Bernadette Graf, *Developmental Disabilities Coordinator*
Patricia Chudacoff, *Project Director*
Patty Dahlquist, *Secretary*

Recognition is given by the Planning Committee to staff members of Health Care Services Agency--Copy Center, Data Management and Graphic Arts

ALAMEDA COUNTY DEVELOPMENTAL DISABILITIES PLANNING AND ADVISORY COUNCIL

B O A R D O F D I R E C T O R S

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Inez Burton (Alternate)
PUBLIC

Alita Buchheit
PUBLIC

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Norma Wolverton
PROFESSIONAL

* Resigned during the year.

DEVELOPMENTAL DISABILITIES
499 FIFTH STREET OAKLAND, CALIFORNIA 94607
(415) 874-6220

DEVELOPMENTAL DISABILITIES
PLANNING and ADVISORY COUNCIL
Mrs. Barbara Reeder, Chairperson
Bernadette Graf, Coordinator

July 1, 1977

Dear Friend:

A project has been undertaken by the Alameda County Developmental Disabilities Advisory and Planning Council to assess the quality of care provided in Alameda County to people with special developmental needs. We ask your assistance by completing the enclosed Survey.

The goal of the project is to develop a comprehensive, action-oriented plan to be presented to the Alameda County Board of Supervisors. It is our hope that the Supervisors will share our concerns by recognizing their responsibility to the many Alameda County residents with developmental disabilities.

The Survey requires attention to only the services you provide and the people you serve. Therefore, you may not be concerned with every page. Summer is here, but won't you please put this Survey at the top of your priority list? The results may be invaluable to you and the people you serve.

We ask that you return the completed Survey by July 15, 1977. A self-addressed envelope has been enclosed for your convenience. If you have questions about the Survey, please call Patricia Chudacoff at 874-6220.

Sincerely yours,

Patricia L. Chudacoff
Project Director

Ruth Moroney, Chairperson
Planning Committee

PLC:pd

Staff is a unit of
ALAMEDA COUNTY
HEALTH CARE SERVICES AGENCY

PLEASE RETURN BY: July 15, 1977

ALAMEDA COUNTY DEVELOPMENTAL DISABILITIES PLANNING AND ADVISORY COUNCIL

499 Fifth Street
Oakland, California 94607
Telephone: (415) 874-6220

_____

s: _____ Phone: ( ) _____

_____ Date: _____

SURVEY FOR SERVICE PROVIDERS

(The Developmentally Disabled population referred to in this Survey includes those disabled by autism, cerebral palsy, epilepsy, mental retardation and neurological handicaps, infancy through aging.)

DEMOGRAPHIC BREAKDOWN

Provide the following information on ONLY the developmentally disabled population served by your agency during the fiscal year 1976 - 77. Specify your fiscal year: From _____ to _____.

A. Total number of developmentally disabled persons served: _____.

B. Number by sex: Male _____ Female _____.

C. Number by geographic location of client's residence:

1. North County _____ (From Albany through Oakland)
2. South County _____ (From San Leandro - South and East)
3. Out of County _____

D. Number by age and primary diagnosis:

Primary Diagnosis	0-35 mos. (Infant)	3-5 yrs. (Pre-School)	6-21 yrs. (School Age)	22-54 yrs. (Adult)	55-over yrs. (Seniors)
	Age				
1. Autism					
2. Cerebral Palsy					
3. Epilepsy					
4. Mental Retardation					
5. Neurological Handicaps					

E. Number by race or ethnic origin (estimate if not stated):

1. Black _____
2. Chinese _____
3. Filipino _____
4. Japanese _____
5. Latin American _____
6. Native American _____
7. Other Asian or Pacific Islander _____
8. White _____
9. Other _____

SERVICES

To identify services now available and to identify developmentally disabled people receiving services, please provide the following information. Directions are as follows:

Column (i) check the primary service(s) which you now provide for developmentally disabled people.

Column (ii) indicate the average number of developmentally disabled people served each month.

Column (iii) indicate the average monthly number of clients on waiting list.

COLUMNS	(i)	(ii)	(iii)
A. DIRECT SERVICES			
1. Early Intervention			
a. Diagnosis and Evaluation			
b. High Risk Follow-Up			
c. Parent Education			
d. Other _____			

COLUMNS	(i)	(ii)	(iii)
2. Funding			
a. Purchase of Services			
b. Provide General Funding			
c. Other _____			

COLUMNS	(i) CHECK PRIMARY SERVICES	(ii) AVERAGE NUMBER SERVED PER MONTH	(iii) AVERAGE NUMBER ON WAITING LIST PER MONTH
3. Education (Private)			
a. Infant Stimulation			
b. Pre-School			
c. Severe-Multiple Handicaps Classes			
d. Trainable Mentally Retarded Classes			
e. Autistic Classes			
f. Educable Mentally Retarded Classes			
g. Learning Disabilities Classes			
h. Orthopedic Classes			
i. Adult Education			
j. Community College			
k. Individual Program (Tutor)			
l. Pre-Vocational Training (School Age)			
m. Other _____			
4. Education (Public)			
a. Infant Stimulation			
b. Pre-School			
c. Development Center Severe Multiple Handicaps			
d. Trainable Mentally Retarded Classes			
e. Autistic Classes			
f. Educable Mentally Retarded Classes			
g. Learning Disabilities Classes			
h. Orthopedic Classes			
i. Adult Education			
j. Community College			
k. Individual Program (Tutor)			
l. Pre-Vocational Training (School Age)			
m. Other _____			
5. Religious Programs			
a. Religious Nurture			
b. Religious Services			

COLUMNS	(i) CHECK PRIMARY SERVICES	(ii) AVERAGE NUMBER SERVED PER MONTH	(iii) AVERAGE NUMBER ON WAITING LIST PER MONTH
6. Social Development			
a. Adult Activity Program for Severely Disabled			
b. Independent Living Skills			
c. Senior Citizen Program			
d. Other _____			
7. Housing-Living Arrangements			
a. Independent Living (with case management)			
b. Independent Living (with attendant care)			
c. Small Home Care (6 or less residents)			
d. Residential Care (more than 6 residents)			
e. Residential Treatment for Disturbed D.D. People			
f. Intermediate Care Facility - D.D.			
g. Skilled Nursing Facility - D.D.			
h. Other _____			
8. Mental Health			
a. Counseling			
b. Psychiatric Treatment			
c. Psychological Services			
d. Twenty-four Crises Care			
e. Other _____			
9. Physical Health			
a. Dental Services			
b. Home Nursing Services			
c. Medical Services			
d. Occupational Therapy			
e. Physical Therapy			
f. Speech Therapy			
g. Special Devices and Adaptive Equipment			
h. Nutrition			
i. Other _____			

COLUMNS

	(i) CHECK PRIMARY SERVICES	(ii) AVERAGE NUMBER SERVED PER MONTH	(iii) AVERAGE NUMBER ON WAITING LIST PER MONTH
10. Recreation / Leisure			
a. After School Program			
b. Camp			
c. Cultural Enrichment (art, dance, music)			
d. Weekend Program			
e. Other _____			
11. Social Services			
a. Case Work			
b. Financial Assistance			
c. Homemaker/Chore Service			
d. Protective Services - Children			
e. Protective Services - Adults			
f. Other _____			
12. Supportive Services			
a. Family Counseling			
b. Day Care for Working Parents			
c. In-Home Respite Care			
d. Out of Home Respite Care			
e. Parent Groups			
f. Other _____			

COLUMNS

	(i) CHECK PRIMARY SERVICES	(ii) AVERAGE NUMBER SERVED PER MONTH	(iii) AVERAGE NUMBER ON WAITING LIST PER MONTH
13. Transportation			
a. Accessible Public Transportation			
b. Private Transportation			
c. Travel Training			
d. Other _____			
14. Vocational Services			
a. Prevocational Training (Adult)			
b. Sheltered Work and Activity			
c. Vocational Training			
d. Vocational Counseling and Job Placement			
e. Other _____			
B. INDIRECT SERVICES			
1. Advocacy (Consumer, Legal, Personal)			
2. Case Management			
3. Ethnic Base Services (Outreach)			
4. Genetic Counseling			
5. Legislation			
6. Manpower Training			
7. Public Information and Education			
8. Research			
9. Protection of Rights			
10. Other _____			

NEEDS

To assess the need for services for developmentally disabled people, please provide the following information. Directions are as follows:

Column (i) check the services for developmentally disabled people NOT currently available in the County.

Column (ii) check the services available but INADEQUATE to serve the Needs of developmentally disabled people.

Column (iii) indicate the number of clients you now serve who would use the checked services if they were available.

Column (iv) assign a priorty value to the five (5) most pressing needs. Beginning with one (1) as the outstanding need working down to five (5).

COLUMNS

	(i)	(ii)	(iii)	(iv)
A. DIRECT SERVICES				
1. Early Intervention				
a. Diagnosis and Evaluation				
b. High Risk Follow-Up				
c. Parent Education				
d. Other _____				

COLUMNS

	(i)	(ii)	(iii)	(iv)
2. Funding				
a. Purchase of Services				
b. Provide General Funding				
c. Other _____				

COLUMNS	(i) CHECK SERVICES NOT AVAILABLE	(ii) CHECK SERVICES AVAILABLE BUT INADEQUATE	(iii) NUMBER OF CLIENTS IN NEED OF SERVICES	(iv) PRIORITY RATING
3. Education (Private)				
a. Infant Stimulation				
b. Pre-School				
c. Severe-Multiple Handicaps Classes				
d. Trainable Mentally Retarded Classes				
e. Austistic Classes				
f. Educable Mentally Retarded Classes				
g. Learning Disabilities Classes				
h. Orthopedic Classes				
i. Adult Education				
j. Community College				
k. Individual Program (Tutor)				
l. Pre-Vocational Training (School Age)				
m. Other _____				
4. Education (Public)				
a. Infant Stimulation				
b. Pre-School				
c. Development Center Severe Multiple Handicaps				
d. Trainable Mentally Retarded Classes				
e. Autistic Classes				
f. Educable Mentally Retarded Classes				
g. Learning Disabilities Classes				
h. Orthopedic Classes				
i. Adult Education				
j. Community College				
k. Individual Program (Tutor)				
l. Pre-Vocational Training (School Age)				
m. Other _____				
5. Religious Programs				
a. Religious Nurture				
b. Religious Services				

COLUMNS	(i) CHECK SERVICES NOT AVAILABLE	(ii) CHECK SERVICES AVAILABLE BUT INADEQUATE	(iii) NUMBER OF CLIENTS IN NEED OF SERVICES	(iv) PRIORITY RATING
6. Social Development				
a. Adult Activity Program for Severely Disabled				
b. Independent Living Skills				
c. Senior Citizen Program				
d. Other _____				
7. Housing-Living Arrangements				
a. Independent Living (with case management)				
b. Independent Living (with attendant care)				
c. Small Home Care (6 or less residents)				
d. Residential Care (more than 6 residents)				
e. Residential Treatment for Disturbed D.D. People				
f. Intermediate Care Facility - D.D.				
g. Skilled Nursing Facility - D.D.				
h. Other _____				
8. Mental Health				
a. Counseling				
b. Psychiatric Treatment				
c. Psychological Services				
d. Twenty-four Crises Care				
e. Other _____				
9. Physical Health				
a. Dental Services				
b. Home Nursing Services				
c. Medical Services				
d. Occupational Therapy				
e. Physical Therapy				
f. Speech Therapy				
g. Special Devices and Adaptive Equipment				
h. Nutrition				
i. Other _____				

COLUMNS	(i) Check Services Not Available	(ii) Check Services Available But Inadequate	(iii) Number of Clients in Need of Services	(iv) Priority Rating
10. Recreation / Leisure				
a. After School Program				
b. Camp				
c. Cultural Enrichment (art, dance, music)				
d. Weekend Program				
e. Other _____				
11. Social Services				
a. Case Work				
b. Financial Assistance				
c. Homemaker/Chore Service				
d. Protective Services - Children				
e. Protective Services - Adults				
f. Other _____				
12. Supportive Services				
a. Family Counseling				
b. Day Care for Working Parents				
c. In-Home Respite Care				
d. Out of Home Respite Care				
e. Parent Groups				
f. Other _____				

COLUMNS	(i) Check Services Not Available	(ii) Check Services Available But Inadequate	(iii) Number of Clients in Need of Services	(iv) Priority Rating
13. Transportation				
a. Accessible Public Transportation				
b. Private Transportation				
c. Travel Training				
d. Other _____				
14. Vocational Services				
a. Prevocational Training (Adult)				
b. Sheltered Work and Activity				
c. Vocational Training				
d. Vocational Counseling and Job Placement				
e. Other _____				
B. INDIRECT SERVICES				
1. Advocacy (Consumer, Legal, Personal)				
2. Case Management				
3. Ethnic Base Services (Outreach)				
4. Genetic Counseling				
5. Legislation				
6. Manpower Training				
7. Public Information and Education				
8. Research				
9. Protection of Rights				
10. Other _____				

PERSONNEL

To determine staffing patterns within programs serving people with developmental disabilities, please indicate the number of people on your staff.

	Total	Full Time	Part-Time
A. Administration			
B. Clerical			
C. Professional			
D. Paraprofessional			
E. Volunteers Providing Direct Services			
F. Other _____			

FINANCIAL INFORMATION

Provide the following information so that the financial responsibility for programs and services may be documented.

A. Total costs for providing services to the developmentally disabled population during the fiscal year 1976 - 77. $ _____.

B. Deficit (if any) for providing these services. $ _____.

C. Sources of funding for the year 1976 - 77 providing services to developmentally disabled:

	Amount
1. Federal (S.S.I, Title XX, grants, etc.)	$ _____
2. State (Regional Centers, CCS, grants, etc.)	$ _____
3. County, City (Revenue Sharing, Recreation, etc.)	$ _____
4. Private (Private Fees, Foundations, etc.)	$ _____
5. Other (specify) _____	
_____	$ _____

D. Projected budget for 1977 - 78. $ _____.

E. Projected deficit for 1977 - 78. $ _____.

F. What services do you now provide which are unfunded?

(a) Service(s)	(b) Amount Unfunded	(c) Who should be Responsible For Funding
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. None: _____(check)		

G. What services do you now provide which are underfunded?

(a) Service(s)	(b) Amount Underfunded	(c) Who should be Responsible For Funding
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. None: _____(check)		

H. What services do you now provide which are fully funded?

(a) Service(s)	(b) Amount Fully Funded	(c) Who should be Responsible For Funding
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. None: _____(check)		

I. What plans do you have for expanding a service or adding a service in 1977 - 78?

(a) Service(s)	(b) Source of Funding
1. _____	_____
2. _____	_____
3. _____	_____
4. None: _____(check)	

J. What plans do you have for curtailing a service or discontinuing a service?

(a) Service(s)	(b) Source of Funding
1. _____	_____
2. _____	_____
3. _____	_____
4. None: _____(check)	

COMPLETED BY: _____

IF YOU DO NOT FIND THIS SURVEY APPLICABLE TO YOUR PROGRAM, BUT WISH TO RECORD YOUR STATEMENT OF CONCERN FOR THE DEVELOPMENTALLY DISABLED POPULATION, PLEASE USE THE BACK OF THIS PAPER.

Thank you.

DEVELOPMENTAL DISABILITIES

499 FIFTH STREET OAKLAND CALIFORNIA

DEVELOPMENTAL DISABILITIES
PLANNING AND ADVISORY COUNCIL

July 8, 1977

Dear Parents, Relatives and Guardians:

The Alameda County Developmental Disabilities Planning and Advisory Council has undertaken a project to evaluate the quality of care provided for people with developmental disabilities in Alameda County.

We recognize that family members are an invaluable source of information. Since we are unable to reach each one personally, we are asking groups who represent developmentally disabled children and adults to complete the enclosed Survey.

The information your members provide will be incorporated into a comprehensive, action-oriented plan to be presented to the Board of Supervisors. It is our hope that the Supervisors will share our concerns by recognizing their responsibility.

We realize that vacations are upon us. May we ask that you try to reach as many members as you can to determine their most important needs as requested in Section V.

For your convenience a self-addressed envelope is enclosed. We ask that you return the completed Survey by July 22, 1977. If you have questions about the project, please call Patricia Chudacoff at 874-6220.

Thank you for your cooperation in this Survey.

Sincerely yours,

Patricia L. Chudacoff

Patricia Chudacoff
Project Director

Ruth Moroney

Ruth Moroney, Chairperson
Planning Committee

PC:pd

ALAMEDA COUNTY
HEALTH CARE SERVICES AGENCY

Please return by: July 22, 1977

ALAMEDA COUNTY DEVELOPMENTAL DISABILITIES PLANNING AND ADVISORY COUNCIL

499 Fifth Street, Oakland, California 94607
Telephone: (415) 874-6220

GROUP SURVEY

Name of Group: _____

Address: _____ Phone: ( ) _____

_____ Date: _____

The Developmentally Disabled population referred to in this Survey includes those disabled by autism, cerebral palsy, epilepsy, mental retardation and neurological handicaps--anyone through age 22.

I. What part of Alameda County does your group represent? Please check.

A. _____ North County (Albany through Oakland)

B. _____ South County (San Leandro - South and East)

C. _____ Total County

D. _____ More than one county

E. _____ Other (Please specify _____)

II. How many developmentally disabled people does your group represent? Please check.

A. _____ 0 - 25 (Specify how many _____)

B. _____ 26 - 50

C. _____ 51 - 75

D. _____ 76 - 100

E. _____ 101 + (Specify how many _____)

III. What developmental disabilities does your group represent? Please check.

A. _____ Autism

B. _____ Cerebral Palsy

C. _____ Epilepsy

D. _____ Mental Retardation

E. _____ Neurological Handicaps

F. _____ All of the developmental disabilities

G. _____ Other (Please specify _____)

IV. Indicate the ages of the developmentally disabled people your group represents? Please check.

A. _____ Pre-school (0 - 5 years)

B. _____ School-age (6 - 21 years)

C. _____ Adults (22 - 54 years)

D. _____ Seniors (55 +)

V. To find the services needed by developmentally disabled people and their families, please provide the following information:

A. In column (i) check the services which do not exist in Alameda County.

B. In column (ii) check the services which do exist but are not available to all developmentally disabled people who need them.

C. In column (iii) put a number next to the services you checked which best indicates the most important services needed by the people your group represents. Begin with (1) for the most important and working down to (5).

SERVICES:	COLUMNS (i)	(ii)	(iii)
1. Adult Day Programs			
2. Advocacy (legal, personal, consumer, etc.)			
3. Counseling			
4. Day Care			
5. Dental Care			
6. Early Intervention (Diagnosis, follow-up, etc.)			
7. Education of Public and Professionals			
8. Financial Assistance for Individuals			
9. Funding for Programs			
10. Infant Stimulation			
11. Independent Living			
12. Medical Services			
13. Recreation/Leisure activities			
14. Religious Programs			
15. Residential Care			
16. Respite			
17. Special Education Classes			
18. Therapy Programs (Speech, O.T., P.T., Behavorial)			
19. Transportation			
20. 24-Hour Crisis Care for the Disturbed Disabled person			
21. Vocational Services			
22. Other _____			

VI. Are you aware of any families in Alameda County with developmentally disabled children or adults who are not receiving services? Yes _____ No _____. If yes, please list their name(s) and address(es) on the back of this paper.

COMPLETED BY: _____

Thank you.

RESPITE QUESTIONNAIRE

DEFINITION: *"Respite" is temporary relief from the care of a handicapped member of your family. Respite may be 1) provided in your home or that of another (In-home respite), or 2) in a facility especially planned and organized to provide respite care.*

I. Who currently cares for the handicapped member of your family?
Relatives _____ Friends/Neighbors _____ Other _____

How much do you pay? _____ How many hours per week do you need them? _____

Under which of the following conditions do you require their help?
VACATIONS: Weekends _____ Evenings _____ Holidays _____
DAILY CARE: Mealtimes _____ Before School _____ After School _____
EMERGENCY: Medical Appointments _____ School Appointments _____
Special Family Gatherings _____ Other _____
CRISIS: Death _____ Illness _____ Hospitalization _____

II. When you need respite, would you use: In-home _____ Facility _____ Both _____

How long would you consider using respite:
In-home: 1 hr. or less _____ 2-4 hrs. _____ 6-10 hrs. _____
24 hrs. _____ 1 week _____ 2 wks. or more _____

Respite Facility: 24 hrs. _____ 1 week _____ 2 wks. or more _____

If respite is availble, how often would you use it?
Daily _____ Weekly _____ Monthly _____ Periodically _____ Never _____

III. If a sliding fee schedule is established for respite, could you pay:
$0 _____ $.50/hr. _____ $1/hr. _____ $2/hr. _____ $3/hr. _____

IV. If you were considering using respite services in your home, what trained person(s) would you feel most comfortable with:
High School Student _____ Young Adult _____ Middle Aged _____
Retired Person _____ Male _____ Female _____ Doesn't matter _____

V. Would you be interested in helping to plan for In-home Respite Services? _____
A Respite Facility? _____

Other background information:
1. Medical diagnosis of family member requiring care: _____
_____ Age _____ Walks _____ Does not walk _____.
2. Number of other children at home _____ Ages _____ _____ _____ _____

VI. Would you like to talk further with someone about Respite Care? _____.

Please return questionnaire to your agency, school, or program or mail to:

Respite Committee
Developmental Disabilities Council
15001 Foothill Blvd.
San Leandro, CA. 94578

Your name: _____
Address: _____
_____
Telephone: _____